

DeKalb: Keeping Abreast with the Hospice Movement

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In the past ten years, a new concept in health care, called hospice, has been sweeping our country. Having been long since established in Europe, the hospice movement was introduced to America in the mid-seventies. Since this time, numerous programs practicing the basic hospice philosophy have been formed, and the demand is increasing for the type of care offered by these programs. The DeKalb County Hospice is just one example of the hospice philosophy being put to excellent work by assisting the terminally ill in the DeKalb County area. In order to examine the special care offered by this specific hospice, it is first necessary to understand the history and basic qualities of hospice care in general.

The development of hospice came about as a result of changing attitudes towards death and dying. During the 19th century, dying and death were recognized as an integral part of the life cycle. Entire families, including children, were exposed to death daily, and dying was an intimate experience shared at home. Now though, this control over one's own fate has shifted from the patient and his family to our institutions and their staff. (Wald, 1980, p.175). Now for some reason, we send our terminally ill to institutions and hospitals to die, often alone and without comfort. Strangely enough, even in these institutions death is regarded as a villain. The death of a patient is perceived as a humiliation and an outrage by the average physician in our culture; to the nursing staff in an

acute-care hospital, it feels like personal defeat (Stoddard, 1978, p.5). In fact, society as a whole tends to ignore the terminally ill and dying. Death is something never discussed, until it is experienced with the loss of a loved one.

As a result of the inadequacies of proper care for the dying, a select few individuals have been able to initiate a new wave of awareness about dying and death. Pioneers such as Dr. Cicely Saunders, founder of St. Christopher's Hospice in England, and Dr. Elisabeth Kubler-Ross in the United States, have brought the subject of dying into the open, and have helped us to learn more about the reality of it (Stoddard, 1978, p.7). These new found attitudes about death have led to a realization of the lack of supportive care for the terminally ill and dying. Thus, it is from this background that the hospice movement developed.

Actually the concept of hospice is not new at all, but can be traced back for many centuries. The term "hospice" comes from a medieval word which stood for a place of shelter for travelers or strangers on journeys (Markel, 1978, p.3). It was here in these roadside hospices that hospitality and care were given to the poor, weak, and sick. Sandol Stoddard, author of an excellent novel on hospices, comments ironically that although the words hospice and hospital share the same root and basic meaning, they both have had completely different roles in our society.

The ancient hospice differed from the modern hospital in many ways. It offered an open door of welcome not only to one sick and dying, but to the hungry wayfarer, the woman in labor,...or the leper with his bell. The common base or denomination of the offering was hospitality

in its original sense of protection, refreshment, "cherishing," and fellowship, rather than the demand of a patient for a cure (Stoddard, 1978, p.10).

Like their ancient counterparts, the hospices of today function to aid the dying in their journey towards death, a process which is viewed as a natural part of the life cycle.

A variety of definitions exist about what the modern hospice is and does today. Basically, hospices offer palliative and supportive care for the dying person, so that the highest possible quality of life for the patient and his family can be maintained when cure is no longer possible, and death is probable in a short time (Perrollaz, 1981, p.46). Emphasis is placed on controlling and preventing pain, along with symptom management of other problems. Social, psychological, and spiritual needs of the patient and his family are also treated. Care of the family continues long after the patient's death.

Hospice care is organized by physicians, is coordinated by nurses, and uses an interdisciplinary approach to offer care 24 hours a day, 7 days a week (Adams, 1984, p.183). Volunteers specially trained in care of the terminally ill play an important role in hospice care. All work towards allowing the willing family to care for the dying patient as long as possible at home, and then providing support when needed.

Surprisingly, five forms of hospices have developed in our country, all of which incorporate the philosophy of hospice care. These include: home care services, hospice teams in hospitals, palliative care units in hospitals, hospices with hospital affiliations, and finally completely autonomous hospices (Wald, 1980, p.174). The ideal form of a hospice is a completely autonomous organization,

with its own specially designed building, for it can offer both inpatient and outpatient services to the terminally ill. One such autonomous hospice is St. Christophers Hospice in London, founded by Dr. Cicely Saunders in the early 1970's. St. Christophers is the "pioneer" of modern hospice, and all others have been modelling their care after the quality offered here.

But whatever the form a hospice takes, all share common elements which make hospice such a special organization. In her book The Hospice Movement, Sandol Stoddard outlines these special qualities.

First and foremost, a hospice is a caring community... Second, a hospice is a community of people who are highly trained in their various skills, particularly in the art and craft of medicine... Third the hospice offers its services and its fellowship, not only to the patient, but to the entire family unit... Fourth, the hospice cares for as many patient-family units as staff and volunteer support will allow without distinction between any of the basis of race, color, creed, or ability to pay... Fifth, the hospice is a community operating on its own principles... and therefore, it must be autonomous in terms of its professional procedure (Stoddard, 1978, p.219-222).

Similarly, the DeKalb County Hospice also shares these same elements of hospice philosophy. This hospice is fairly new, and provides care in the home setting for terminally ill individuals in DeKalb County. The definition and goals of this hospice are not unlike those of the general hospice movement.

Hospice is a support system providing physical, emotional, social, and spiritual comfort for individuals and their families

copied with a potentially terminal illness. The goals of DeKalb County Hospice are: to provide compassionate care for potentially terminally ill patients and their families, to give family and friends an opportunity to share actively in the care, comfort, and support of their love one, and to help make the patient's life as happy, comfortable, and meaningful as possible (DeKalb County Hospice pamphlet).

Special emphasis has been paid to the specific wording of this pamphlet, which was distributed throughout DeKalb County. Instead of stating the direction of hospice services toward the dying, the words "potentially terminally ill patients" are used. This word choice is used in order to not frighten those who might not have recognized or accepted their condition as terminal.

The DeKalb County Hospice offers primarily home care to patients. They are referred to the hospice mostly by physicians, although family members may call and request help. Only terminally ill individuals, who have about less than six months to live, are admitted into this particular hospice program.

The patient and family is first oriented to the program by a hospice nurse. She evaluates the entire situation, and assesses the palliative and supportive care required by the individual. Then, in collaboration with the patient's physician, proper care is initiated. Often the help of a home health nurse from a local agency is acquired. Specially trained hospice volunteers also visit the home, and are in direct communication with the hospice office. As stated in this organization's goal, emphasis is placed on making the individual's last days as comfortable and as fulfilling as possible.

But unlike a large number of hospices, the DeKalb County Hospice can not offer inpatient services, for it is not an autonomous hospice, nor is it affiliated with a hospice program in a hospital. Instead hospice care is provided primarily in the patients home. As a result, if the patient must be admitted to a medical facility, special steps are taken to provide for continuing hospice care. This allows for compassionate care of the patient in institutions which may not have such a caring attitude towards the dying.

The demand for this hospice's services is steadily increasing in the DeKalb County area. As more physicians see the benefits of hospice care in improving the quality of a terminally ill patient's life, hopefully more will be willing to collaborate with this program. Likewise, as more families are assisted by hospice, news of the special services offered by this program will spread. The DeKalb County Hospice, like the entire hospice movement, is well on its way to providing the long needed support to those experiencing the last part of their journey through life.

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Hospice Experience Log

Sept. 4 This evening was the hospice orientation meeting for prospective volunteers. Karen Hagen, the executive director of the DeKalb County Hospice program conducted the entire meeting. She first gave us a summary of the historical background of both the hospice concept in general, and of the DeKalb County Hospice. We watched two video presentations. One was a slide presentation about the DeKalb Hospice, and the other a video of a hospice patient who dies at home. The role of a hospice volunteer was discussed after the movie, along with information about the next meeting. I really enjoyed this session, and learned a lot about what hospice does. The video presentation was excellent!

Sept. 14 Tonight was the first night of our orientation program. We listened to talks by both Karen Hagen and by a sociology teacher from NIU. This man teaches classes about dying and death, which were the topics for this evening. We did a few exercises to help facilitate discussion about dying and death. At first I thought that this evening would turn out to be kind of morbid, but I actually did learn a lot. Death was something that was not given much attention in my nursing classes, and I think that this evening really assisted me in beginning to seriously explore my own feelings about death. This evening's lecture also came at a pertinent time for me, after just experiencing my grandpa's death one month ago.

Sept. 15

Today was the second part of our orientation. It was a long day--from 9:00 am to 4:30 pm. The morning began with a basic presentation geared towards lay people about cancer and its treatment. We then talked about Hospice, and its interventions for supportive care of the cancer patient. Pain management, diet therapy, and emotional support were some of the topics covered. Our final topic of discussion was about funerals. We took a tour of a local funeral home. This tour included talks by the funeral director about embalment and casket choosal. After our tour we all went home. It was really depressing. I was tired after a long day of sitting and listening to talking, and even though the material was interesting, I was really bummed when I got home. It seemed so insignificant listening to people talking about going out to parties in the dorm, when I had just gotten back from looking at caskets! But I really did learn a lot today.

Sept. 16

This was the last day of our orientation! We talked about grieving and bereavement, and hospice's role in assisting families through these processes. I thought today's session was very uplifting compared to the others. Karen ended the discussion today by trying to put everything we've covered into the perspective of our roles as hospice volunteers. Even though this weekend session was long and at times somewhat depressing, I feel that it was of invaluable worth to me! The topics that were discussed and the thinking that they initiated really assisted me in helping to discover my own feelings about this subject. I'm ready to put my learning to work now with a patient!

Oct. 3 Karen called today with my first patient assignment!

This patient is a 70 year old man who lives in DeKalb. He was diagnosed with cancer of the bowel and probable metastasis to the bone and liver. He had a colostomy, and was being visited regularly by a public health nurse. Karen gave me information about this man's family history, and directions to his home in DeKalb. She added that the patients wife has got "a pretty good hold on the situation," and that she would probably just need me to spend some time at the home to give his wife time to run errands. Karen said she would talk to his wife tomorrow, and let them know who I was, and that I would be contacting them on Monday.

Oct. 9 I called and talked with my patient's wife today to introduce myself. She sounded like she had been waiting for my call. I told her that if she had any questions for me about anything that I would try my best to help find answers for her. She told me that she would get her questions ready. We decided that I would visit tomorrow at 1:00 pm.

Oct. 10 Today I went to visit my patient and his wife. I was a little nervous, because I know that this visit would be different than anything I had ever done before! When I arrived, his wife asked me if I could stay for a couple of hours so that she could run some errands, which was perfectly fine with me. She took me on a short tour of their home, so I would know where everything was. They have a huge house, which is shaped like an octagon. On the tour, I couldn't figure out where her husband was, but then she finally introduced me to him. His was in far worse shape than I had imagined from our telephone conversation, for he was lying in a hospital bed in the middle of their bedroom, he was very pale, and kept drifting

in and out of sleep. Before his wife left, she made sure that he understood who I was and why I was there. He became a little more alert, and was talking to me about NIU. Then he went back to sleep. Luckily I had brought something to read, so I just sat next to his bed and read. If anything today I learned the importance of just being there for a patient, and not really saying anything. Often when I would look up I would catch him, with his eyes half open just looking to make sure I was still there. Sometimes he would wake up and ask for something to drink, so I helped him. Towards the end of the afternoon he began having bad dreams, or hallucinations, or something, because he kept mumbling to himself, or talking to people who were not there. Luckily his wife came home shortly after he began doing this, and she said that it had been happening a lot in the past twenty-four hours. She asked that I tell Karen when I call her. She was so appreciative to me for the time I spent with him. Actually I felt like I didn't do enough, and even though I was there for three hours, I felt like I really didn't deserve all her thank-yous. I told her that I would let Karen know about her husbands condition, and that I would call her (the wife) back about visiting again on Friday when I get back from the hospital tomorrow. I was right, today was a different experience, but I felt good in knowing that at least I could help them out. When I got home I called Karen to let her know about my visit. She said that she would go out to visit him tomorrow, because she did not think he was as bad as he was today.

Oct. 11 I called my patient today when I got home. His wife answered, and said that she was very sad because he died this afternoon. I told her how sorry I was and asked if I could do anything for her, but she

said no, not at this moment. I told her to call me if she needs anything at all. I called Karen, and she said that she had just found out too. She asked me if I was all right. I was sad and felt sorry for his wife, but I was O.K.

***I tried to call his wife back about a week after his death, but each time I tried there was no answer.

I spoke with Karen a couple of times during the next few months. She called me in mid-November to tell me that she might possibly have another person for me, but the situation never worked out. I had asked Karen that if she had any new admits in the area that I would love to go with her, but unfortunately this never worked out either. Still I feel that I have benefited greatly from this entire experience. Not only have I learned a lot about the fantastic concept of hospice care, but I have also had the opportunity to put this knowledge to use with helping a patient and his wife. I also think that I now have a much more concrete hold on my feelings about death, whereas before I tended, like others, to ignore this subject. Everything that I learned from this experience will definitely be able to be applied in my future role as a nurse, especially if I am able to work in neonatal intensive care nursing. I feel lucky that I have had this experience...too bad something like this can not be experienced by everyone in the nursing program here.

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